



General Assembly

February Session, 2014

***Raised Bill No. 285***

LCO No. 1849



Referred to Committee on COMMITTEE ON CHILDREN

Introduced by:  
(KID)

***AN ACT CONCERNING NEWBORN SCREENING FOR KRABBE DISEASE.***

Be it enacted by the Senate and House of Representatives in General Assembly convened:

1 Section 1. Section 19a-55 of the 2014 supplement to the general  
2 statutes is repealed and the following is substituted in lieu thereof  
3 (*Effective July 1, 2014*):

4 (a) The administrative officer or other person in charge of each  
5 institution caring for newborn infants shall cause to have administered  
6 to every such infant in its care an HIV-related test, as defined in section  
7 19a-581, a test for phenylketonuria and other metabolic diseases,  
8 hypothyroidism, galactosemia, sickle cell disease, maple syrup urine  
9 disease, homocystinuria, biotinidase deficiency, congenital adrenal  
10 hyperplasia and such other tests for inborn errors of metabolism as  
11 shall be prescribed by the Department of Public Health. The tests shall  
12 be administered as soon after birth as is medically appropriate. If the  
13 mother has had an HIV-related test pursuant to section 19a-90 or 19a-  
14 593, the person responsible for testing under this section may omit an  
15 HIV-related test. The Commissioner of Public Health shall (1)

16 administer the newborn screening program, (2) direct persons  
17 identified through the screening program to appropriate specialty  
18 centers for treatments, consistent with any applicable confidentiality  
19 requirements, and (3) set the fees to be charged to institutions to cover  
20 all expenses of the comprehensive screening program including  
21 testing, tracking and treatment. The fees to be charged pursuant to  
22 subdivision (3) of this subsection shall be set at a minimum of fifty-six  
23 dollars. The Commissioner of Public Health shall publish a list of all  
24 the abnormal conditions for which the department screens newborns  
25 under the newborn screening program, which shall include screening  
26 for amino acid disorders, organic acid disorders and fatty acid  
27 oxidation disorders, including, but not limited to, long-chain 3-  
28 hydroxyacyl CoA dehydrogenase (L-CHAD) and medium-chain acyl-  
29 CoA dehydrogenase (MCAD).

30 (b) In addition to the testing requirements prescribed in subsection  
31 (a) of this section, the administrative officer or other person in charge  
32 of each institution caring for newborn infants shall cause to have  
33 administered to every such infant in its care (1) a screening test for  
34 cystic fibrosis, (2) a screening test for severe combined  
35 immunodeficiency disease, [and (3) on and after January 1, 2013,] (3) a  
36 screening test for critical congenital heart disease, and (4) on and after  
37 January 1, 2015, a screening test for globoid cell leukodystrophy. Such  
38 screening tests shall be administered as soon after birth as is medically  
39 appropriate.

40 (c) On and after the occurrence of the following: (1) The  
41 development and validation of a reliable methodology for screening  
42 newborns for adrenoleukodystrophy using dried blood spots and  
43 quality assurance testing methodology for such test or the approval of  
44 a test for adrenoleukodystrophy using dried blood spots by the federal  
45 Food and Drug Administration; and (2) the availability of any  
46 necessary reagents for such test, the administrative officer or other  
47 person in charge of each institution caring for newborn infants shall  
48 cause to have administered to every such infant in its care a test for

49 adrenoleukodystrophy.

50 (d) The provisions of this section shall not apply to any infant whose  
51 parents object to the test or treatment as being in conflict with their  
52 religious tenets and practice. The commissioner shall adopt  
53 regulations, in accordance with the provisions of chapter 54, to  
54 implement the provisions of this section.

This act shall take effect as follows and shall amend the following sections:		
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Section 1	July 1, 2014	19a-55
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**Statement of Purpose:**

To require newborn screening for globoid cell leukodystrophy.

*[Proposed deletions are enclosed in brackets. Proposed additions are indicated by underline, except that when the entire text of a bill or resolution or a section of a bill or resolution is new, it is not underlined.]*